



Published in final edited form as:

*J Clin Psychol Med Settings*. 2014 September ; 21(3): 234–243. doi:10.1007/s10880-014-9400-9.

## Shared Decision-Making among Caregivers and Health Care Providers of Youth with Type 1 Diabetes

Jessica M. Valenzuela<sup>1</sup>, Laura B. Smith<sup>2</sup>, Jeanette M. Stafford, S. Andrews, Ralph B. D'Agostino Jr.<sup>3</sup>, Jean M. Lawrence<sup>4</sup>, Joyce P. Yi-Frazier<sup>5</sup>, Michael Seid<sup>6</sup>, and Lawrence M. Dolan<sup>7</sup> For The SEARCH for Diabetes in Youth Writing Group

<sup>1</sup>Nova Southeastern University, Center for Psychological Studies, Fort Lauderdale, FL

<sup>2</sup>University of South Florida Diabetes Center, Department of Pediatrics, Morsani College of Medicine, University of South Florida, Tampa, FL

<sup>3</sup>Wake Forest School of Medicine, Department of Biostatistical Sciences, Division of Public Health Sciences, Winston-Salem, NC

<sup>4</sup>Department of Research & Evaluation, Kaiser Permanente Southern California, Pasadena, CA

<sup>5</sup>University of Washington School of Medicine, Department of Pediatrics, Seattle, WA

<sup>6</sup>Cincinnati Children's Hospital Medical Center, Department of Pediatrics, Division of Pulmonary Medicine, Cincinnati, OH

<sup>7</sup>Cincinnati Children's Hospital Medical Center, Department of Pediatrics, Division of Endocrinology, Cincinnati, OH

### Abstract

The present study aimed to examine perceptions of shared decision-making (SDM) in caregivers of youth with type 1 diabetes (T1D). Interview, survey data, and HbA1c assays were gathered from caregivers of 439 youth with T1D aged 3–18 years. Caregiver-report indicated high perceived SDM during medical visits. Multivariable linear regression indicated that greater SDM is associated with lower HbA1c, older child age, and having a pediatric endocrinologist provider.

Address correspondence to: Jessica M. Valenzuela, PhD, Nova Southeastern University, Center for Psychological Studies, 3301 College Ave., Fort Lauderdale, FL 33314, Jessica.Valenzuela@nova.edu Office: 954-262-5737, Fax: 954-262-3859.

#### Informed Consent

All procedures followed were in accordance with the ethical standards of the responsible committees on human experimentation (California: Kaiser Permanente Southern California; Carolinas: University of South Carolina, Medical University of South Carolina, Orangeburg Hospital System, McLeod Hospital, Palmetto Health, Spartanburg Regional Health System, Greenville Hospital System now Greenville Health System, AnMed Health, University of North Carolina at Chapel Hill; Colorado: Colorado Multiple Institutional Review Board, Navajo Nation Human Research Review Board; Hawaii: Pacific Health Research Institute, Kuakini Medical Center/Kuakini Geriatric Care, Inc., University of Hawaii, Kaiser Permanente Hawaii; Ohio: Cincinnati Children's Hospital, Fort Hamilton Hughes Hospital, St. Luke Hospital, St. Elizabeth Medical Center, University of Cincinnati Medical Center, The Christ Hospital, The Jewish Hospital of Cincinnati, Mercy Health Partners, Middletown Regional Hospital, McCullough-Hyde Memorial Hospital, Good Samaritan Hospital, Bethesda North Hospital, Tri-Health, The Ohio Department of Health; Washington: Seattle Children's including University of Washington approval, MultiCare Health System, Virginia Mason/Benaroya Research Institute, Swedish Medical Center, Group Health Cooperative, Western IRB) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

#### Conflict of Interest

Jessica M. Valenzuela, Laura B. Smith, Jeanette M. Stafford, Ralph B. D'Agostino Jr., Jean M. Lawrence, Joyce P. Yi-Frazier, Michael Seid, and Lawrence M. Dolan declare that they have no conflict of interest

Multiple logistic regression found that caregivers who did not perceive having made any healthcare decisions in the past year were more likely to identify a non-pediatric endocrinologist provider and to report less optimal diabetes self-care. Findings suggest that youth whose caregivers report greater SDM may show benefits in terms of self-care and glycemic control. Future research should examine the role of youth in SDM and how best to identify youth and families with low SDM in order to improve care.

## Keywords

shared decision-making; type 1 diabetes; communication; patient participation

The Institute of Medicine (IOM) has emphasized the importance of shared decision making (SDM) in improving the quality of healthcare in the United States (IOM, 2009; IOM, 2001). SDM involves a bidirectional information exchange in which patients are active partners in decision-making with their health care provider (Charles, Gafni, & Whelan, 1999; Makoul & Clayman, 2006). In adults with diabetes, studies indicate that patient participation in decision-making and patient-centered physician communication styles may increase satisfaction with care, motivation for disease management, and regimen adherence (Golin, DiMatteo, Duan, Leake, & Gelberg, 2002; Levetown, 2008; Maddigan, Majumdar, & Johnson, 2005; Williams, Freedman, & Deci, 1998). Furthermore, a recent review found that interventions which facilitate patient participation in care (e.g., guiding patients to participate in diabetes consultations) are a promising means of improving diabetes care behaviors and biomedical health outcomes such as glycemic control (van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003).

Few studies have examined SDM in a pediatric care setting. The pediatric literature suggests that health care providers underestimate the degree to which caregivers would like to participate in directing their child's care and that adolescents with chronic illnesses value the involvement of their caregivers in medical visits more than their healthy peers (Klostermann, Slap, Nebrig, Tivorsak, & Britto, 2005; Worchel et al., 1995). Most pediatric research examines caregiver/parent decision-making in acute treatment situations, e.g., utilization of antibiotics/vaccinations, treatment decisions for high-risk newborns, end of life or surgical treatment in inpatients (Gagnon & Recklitis, 2003; Merenstein, Diener-West, Krist, Pinneger, & Cooper, 2005; Peerzada, Schollin, & Håkansson, 2006; Sturm, Mays, & Zimet, 2005). However, there are significant differences between these acute decisions and a chronic care model, which requires an ongoing patient-provider partnership and considerable patient self-management (Montori, Gafni, & Charles, 2006). Recent research that included children with asthma and with special health care needs found that increased caregiver and child participation in medical visits is associated with fewer symptoms, increased caregiver satisfaction with care, and decreased healthcare utilization and costs (Fiks, Mayne, Localio, Alessandrini, & Guevara, 2012; Skinner et al., 2004; Wissow et al., 1998).

Given these preliminary findings regarding SDM in the context of pediatric care, the present study aims to describe caregiver-report of SDM with their child's health care provider in a

large, representative sample of youth with type 1 diabetes (T1D). Additionally, we examine associations between SDM and sociodemographic and clinical characteristics in order to explore possible disparities in SDM practices. Findings from this study may enhance our understanding of the frequency of SDM in pediatric diabetes provider-caregiver interactions, and also help us understand whether pediatric diabetes providers should consider SDM an important part of clinical care (e.g., if it is associated with improved outcomes). Finally, findings will help us to understand which subgroups of families and healthcare providers are at greatest risk for reduced SDM in clinical interactions.

## Methods

### Procedure

SEARCH is a multi-center study that, in 2001, began conducting population-based ascertainment of youth who were < 20 years of age when diagnosed with diabetes (SEARCH for Diabetes in Youth Study Group, 2004). Participants were all residents of defined populations defined based on either their geographic location or by enrollment in large managed health care plans. SEARCH recruited youth from geographically-defined populations in Ohio, Colorado, South Carolina, and Washington, Indian Health Service beneficiaries from four American Indian populations, and enrollees in managed health care plans in Hawaii and California. Individuals who were active duty military or institutionalized were excluded from participating. The current study includes incident cases of diabetes in these populations. Cases were identified based on networks of pediatric and adult endocrinologists, as well as hospitals, electronic health records, administrative health data systems, and diabetes registries. Capture recapture analysis has shown that case ascertainment has a high degree of completeness (SEARCH for Diabetes in Youth Study Group, 2006). Institutional review board(s) for each site approved the study protocol. All registered cases were asked to complete a brief initial survey; survey respondents were invited to a research visit. Participants whose diabetes was incident in 2002–2005 who completed the baseline study visit were additionally invited for follow-up visits at 12, 24, and 60 months after their initial study visit. Each site maintained in contact with participants through study newsletters, requests for address updates, birthday and holiday cards, and other methods.

Study visits were conducted by study staff in clinical research settings, health clinics, or the participants' homes. All staff were trained and certified on the standardized protocol and manual of procedures. After obtaining informed consent and assent (for youth < 18 years) at the study visit, staff took physical measurements, administered questionnaires to youth and caregivers (most commonly a parent), and obtained fasting blood samples from metabolically stable youth (defined as no episodes of DKA during the previous month). Participants who had an episode of DKA in the past month were rescheduled for a future date when they were metabolically stable. Interviewers elicited information from caregivers about youths' demographic characteristics, comorbidities and complications, current treatment and medications, and use of health care services. All data collection forms were available in English and Spanish, with a bilingual staff member or an on-site translator present at data collection visits.

## Measures

**Provider/Clinical Factors**—Type of provider for diabetes care was based on caregiver-report of the primary health care provider “responsible for their child’s diabetes care” as selected from a limited response set including pediatric endocrinologist, nurse practitioner, pediatrician, family practice doctor, general practice doctor, etc. Due to the limited frequency with which other providers were reported, these responses were combined into three possible categories (pediatric endocrinologist, nurse practitioner, or other provider).

Insulin regimen was based on caregiver-report and classified as conventional or intensive. Patients classified as having a conventional regimen included those using an intermediate acting insulin (e.g., NPH) rather than a long acting basal insulin. Conventional insulin regimens typically involve fewer injections per day (i.e., 2–3) and are less flexible in that they necessitate following a set schedule of meal times and food amounts. Patients classified as having an intensive regimen (also called basal-bolus regimen) included those using a long-acting basal insulin (e.g., glargine) or an insulin pump. Intensive insulin regimens typically involve more injections per day (i.e., 4–6) or the use of an insulin pump and are more flexible in terms of meal timing and food amounts. Patients are prescribed a regimen type based on a variety of factors, including patient preference, family resources, healthcare provider preference or standard practice, and patient adherence to their regimen. The increased use of intensive insulin regimens (i.e., basal-bolus regimens and insulin pumps) in youths “has been associated with more children reaching ADA blood glucose targets” (American Diabetes Association, 2013).

Glycemic control was assessed from blood samples drawn at the 24-month study visit. Blood samples were processed locally and shipped on ice to a central laboratory (Northwest Lipid Laboratory, University of Washington, Seattle, WA) for analysis. A dedicated ion exchange unit, Variant II (Bio-Rad; Diagnostics, Hercules, CA), quantified the HbA1c. The reference range for normal HbA1c values is 3.9% to 6.1%. The optimal target values for HbA1c in youth are <8.5% for persons <6 years of age, <8.0% for 6- to 12-year-olds, <7.5% for 13- to 18-year-olds, and <7.0% for persons >18 years of age (Silverstein et al., 2005).

**Patient/Family Factors**—Youths’ race and ethnicity was reported by caregivers based on the 2000 census questions and categorized as Hispanic/Latino (regardless of race), non-Hispanic White, Black, and Asian/Pacific Islander. Youth who reported multiple races were sorted into a race category using the “plurality approach.” The plurality approach “assigns responses based on data from the National Health Interview Survey (NHIS)... All responses in a particular multiple-race group are assigned to the category with the highest NHIS proportion” based on data about which racial category is most often identified as “primary race” by respondents in that group (Ingram et al., 2003, p. 3). Caregiver education was also ascertained from caregiver-report and categorized as less than high school, high school graduate, some college, or college graduate for the caregiver with the highest education.

**Self-Care Composite Score**—A Self-Care Composite (SCC) score consisted of 14 items based on caregiver-report, many of which were adapted from the Diabetes Self-Management Profile (DSMP; Harris et al., 2000). Included items asked about self-care behaviors over the

past three months, including items about hypoglycemia (e.g., does your child keep something with him/her to eat in case his/her blood sugar gets too low), diet (e.g., indicate which dietary recommendations you have received for your child from health care providers and how frequently you use this method), and blood glucose monitoring (e.g., how often have you or your child tested his/her blood sugar). Consistent with the DSMP standard interview structure, the response options and scoring ranges varied across the 14 items. A total SCC score was obtained by summing responses across the items and possible scores ranged from 0 to 61, with higher scores indicating more optimal self-care.

**SDM Composite Score**—A composite score was calculated based on caregiver-report of the SDM items from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey Supplemental Item Set for Children with Chronic Conditions (Agency for Healthcare Research and Quality, 1998). These 4 items on the CAHPS were specifically developed to measure caregivers' experiences with SDM. Caregivers initially responded to the item "In the last 12 months, were any decisions made about your child's health care?" If caregivers responded "no" to this item, they were not asked additional questions about healthcare decisions nor did they receive a SDM composite score. Those who responded "yes," were asked 4 items to assess how often their child's health care provider included them in decision-making. Items included: "When decisions were made in the last 12 months, how often did your child's doctors or other health care providers (1) offer you choices about your child's health care?; (2) discuss with you the good and bad things about each of the different choices for your child's health care?; (3) ask you to tell them what choices you prefer, (4) involve you as much as you wanted?" Participants indicated their response choice to each item as follows: 1 = "Never," 2 = "Sometimes," 3 = "Usually" and 4 = "Always," with higher scores indicative of greater SDM. Caregivers' scores on these four items were averaged to create a composite SDM score which could range from 1 to 4.

## Design and Statistical Analysis

The sample for these secondary data analyses was limited to responses from caregivers of youth < 18 years of age with T1D who completed the surveys necessary for the SDM composite and the SCC. These questionnaires were only completed by caregivers at the time of the 24-month SEARCH study visit. Demographic and clinical characteristics were summarized using count (%) or mean  $\pm$  SD. Multivariable linear regression analysis was used to evaluate associations between patient demographic and clinical variables (age at visit, race/ethnicity, highest caregiver education, provider type, diabetes regimen type, self-care, and glycemic control) and the outcome measure, the caregiver SDM composite score. Logistic regression was conducted to explore how these same demographic and clinical variables were associated with caregiver's perception of having made "any decisions about their child's health care" (yes/no) in the last 12 months. Both regression analyses were additionally run with duration of disease included in the model. Statistical analyses were conducted using SAS software, version 9.2 (SAS Institute, Cary, NC, USA). Results were considered significant if the two-sided p-value was < 0.05.

## Results

The study sample is composed of caregivers of 439 youth who were between the ages of 3.6 to 17.9 years with mean T1D duration of  $3.2 \pm 0.7$  years at the time of their 24 month follow-up visit (Table 1). They were predominantly non-Hispanic, White youth with at least one caregiver who had attained some college education. Almost 90% of the youth were on an insulin pump or basal/bolus therapy, and 66.4% were managed by a pediatric endocrinologist. ADA guidelines for HbA1c were met for 37.2% of youth. Another 40.6% of youth had intermediate levels of control, defined as not meeting ADA guidelines but  $<9.5\%$  (Petitti et al., 2009). Caregivers reported an average SCC score of  $47.1 \pm 7.8$  out of a total possible score of 61. The 14-item SCC had adequate internal consistency (Cronbach's  $\alpha = 0.80$ ). On average, 77.2% ( $47.1/61.0$ ) of ideal self-care behaviors were performed.

Of these caregivers, 334 (76.1%) reported that decisions had been made regarding their child's health care over the past 12 months. The frequency distribution for each item in the SDM measure is shown in Table 2 for these caregivers. For every item, over 80% of caregivers (ranging from 80.5% – 92.3%) reported that their provider “usually” or “always” interacted with them in ways consistent with SDM. Thirty-nine percent (39.8%;  $N = 133$ ) of all caregivers gave their child's health care provider a perfect score on the SDM composite (rated every item a “4” for “always”). The mean SDM score was 3.40 ( $SD = 0.72$ ). The 4-item SDM scale had good internal consistency (Cronbach's  $\alpha = 0.90$ ).

Table 3 shows the variables included in a multivariable linear regression where the SDM score was the dependent variable. Of the 334 caregivers that reported that decisions had been made over the past 12 months, 282 were included in the linear regression due to exclusions for missing data (primarily A1c). The overall regression equation was significant,  $R^2 = .08$ . Among the patient/family factors that we examined, only older age of youth with T1D was associated with greater caregiver-report of SDM ( $P = .01$ ). Among the provider and clinical characteristics, caregivers of youth whose primary source of diabetes care was a pediatric endocrinologist reported greater SDM ( $P = .04$ ) while lower HbA1c levels, indicating better glycemic control, were associated with greater SDM ( $P = .01$ ). Race/ethnicity, caregiver education, insulin regimen intensity, and diabetes self-management score were not significant predictors of SDM. Inclusion of duration of diabetes did not change the results substantially (data not shown here).

Table 4 shows the variables included in the multiple logistic regression where the outcome was whether the caregiver reported that any healthcare decisions were made in the past 12 months (yes/no). A little less than a quarter (23.9%) of the caregivers in the sample reported no health care decisions were made for their child over the past year. Three hundred and seventy-five observations were included in the logistic regression after exclusion for missing data (primarily A1c). Caregivers who reported higher self-care scores (i.e., better disease management) were more likely to have indicated that decisions about their child's care had been made in the last 12 months (odds ratio [OR] = 1.04, 95% Confidence Interval [CI]: 1.01–1.08,  $p = 0.02$ ). In addition, those who identified their provider as a pediatric endocrinologist were also more likely to report that decisions had been made (OR = 1.74, 95% CI: 1.05–2.90,  $p = 0.03$ ). Race/ethnicity and caregiver education were not significant in



the model. Inclusion of duration of diabetes did not change the results substantially (data not shown here). Therefore, tests of the pairwise comparisons are not presented. None of the other variables assessed were independently associated with caregiver perception of health care decisions in the last 12 months.

## Discussion

Our findings suggest that many caregivers of youth with T1D may be satisfied with their child's health care provider's SDM efforts. In fact, on each of the four SDM items measured, over 80% of those who indicated that they had made a healthcare decision in the last year perceived frequent SDM. This proportion of caregivers is somewhat higher than that of other groups of caregivers whose children have chronic health conditions (e.g., 65%; Fiks, Localio, Alessandrini, Asch, & Guevara, 2010). In part, this may be representative of a sample of youth with largely adequate to fair glycemic control (78% of youth had HbA1c <9.5%; Mean HbA1c% =  $8.5 \pm 1.5$ ), as compared to studies of SDM in youth with asthma that have included a wider range of youth from moderate to severe asthma. In addition, most other studies have examined SDM in the context of community primary care. However, almost seventy percent of youth in the present study receive their diabetes care from a diabetes specialist. Higher quality care and improved outcomes have been associated with receiving care from a physician with an endocrinology specialization and in a diabetes clinic (Ho, Marger, Beart, Yip, & Shekelle, 1997; Zgibor, Songer, Kelsey, Drash, & Orchard, 2002). Our findings are consistent with this in that SDM, one component of high quality care, is more likely to be experienced by caregivers of youth seen by a pediatric endocrinologist.

We also found an association between tighter glycemic control and SDM. The findings of the present study, which is cross-sectional in nature, cannot determine the directionality of this relationship. In fact, it is likely that the relationship is bidirectional in nature. Pediatric and adult asthma research has found reduced symptoms and improved clinical outcomes, such as lung functioning, to be associated with SDM (Skinner et al., 2004; Wilson et al., 2010).

In addition, research in adults with diabetes suggests that SDM is related to improvements in satisfaction with care and in the self-management behaviors of patients with diabetes (Beverly et al., 2012; Golin et al., 2002; Heisler, Cole, Weir, Kerr, & Hayward, 2007; van Dam et al., 2003). These improvements are potential mechanisms by which SDM could result in improved clinical outcomes in this population. However, it is also possible that providers engage less in SDM with caregivers of youth with poor glycemic control because they are more directive with these families (e.g., providing less family choice in treatment changes). With the exception of the present study, there is limited research examining SDM and clinical outcomes in youth with T1D. Our findings suggest a need for more research into the potential clinical benefits of SDM and clinical factors impacting patient and physician communication. In addition to disease/clinical variables, we examined potential sociodemographic variables associated with SDM and found higher ratings of SDM were associated with older age of the youth with T1D. This finding may reflect a number of changes as children age. For example, families may become more comfortable being

involved in medical decision making with adolescents, and/or providers may solicit more input from families as children get older. The reason for this relationship in the present study is unclear, and should be further investigated. It is also important to note that the present study does not examine the extent to which providers or caregivers included youth in decision-making, so we cannot currently determine how these complex interactive decisions were negotiated within the medical visits. In fact, very few studies have examined child involvement or triadic (i.e., provider-caregiver-child) participation in care, but existing studies have more generally found limited participation of youth in medical visits (Beresford & Sloper, 2003; Tates & Meeuwesen, 2001). Future research on caregiver and adolescent participation in SDM should examine the potential for SDM to be protective during adolescence, as shared responsibility for self-care has been shown to promote self-management in this developmental period (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008); as well as the potential for SDM to predict successful transition from pediatric to adult diabetes care (Miller & Harris, 2011).

No association between socioeconomic status or child race/ethnicity and caregiver-reported SDM was found. The literature on adults has indicated that “patient education, health literacy, and sociocultural issues” are important barriers that can lead to poor SDM in low income and racial/ethnic minority patients, especially African American patients seen in primary care (Peek et al., 2009). The present study consisted of a sample that was predominantly White with higher than average parent education. Therefore, additional research on SDM with large, diverse samples of youth is needed in order to better understand the experiences and preferences of low-income and racial/ethnic minority families of youth with T1D. However, at least one other study of SDM in children with chronic health needs has found no disparities in caregiver-report of SDM due to race/ethnicity or income (Fiks et al., 2010). Systems of care in which children with chronic illness are seen vary in multiple ways from the systems of care in which adults are typically seen, e.g., differences in developmental focus, access to family-centered care, etc. (Reiss, Gibson, & Walker, 2005). These differences in pediatric care may explain the limited evidence of disparity in this population, but replication of this finding with a more comprehensive measure of SDM and a larger, more diverse sample is needed.

Almost a quarter of all caregivers in the present study reported that no decisions were made about their child’s diabetes care over the last year. This finding was surprising given the complexity of treatment decisions in pediatric T1D, particularly among youth with intensive insulin regimens, which made up a large portion of the sample. It may be that this question served as an indicator for poor participation in care, given that caregivers who perceived that no decisions were made about their child’s disease management may be those that are least involved in these decisions. However, there is no way to determine in the present study whether or not a response of “no healthcare decisions” is an indicator of particularly low SDM since no other information on number of health care encounters, caregiver participation, or SDM were available for these families.

Findings from exploratory analyses were consistent with other results; caregiver-report of “no perceived care decisions” was more common in youth who were not seen by pediatric specialists and was associated with poorer caregiver-reported diabetes self-care (e.g., less



blood glucose monitoring). Findings from this study should be considered in the context of some important limitations. First, the cross-sectional nature of the present study precludes our ability to infer causality. Finally, SDM was measured retrospectively using caregiver-report, thus youth were not given an opportunity to respond about their perceptions of SDM and caregiver recall bias is also possible. While this paper focuses on the perception of the caregiver and not the youth with diabetes, more research on the role of youth in SDM is needed.

Additionally, a large portion of the cohort reported “perfect” SDM, suggesting that the measure may be prone to ceiling effects, which are common among similar measures (e.g., Bradley, Plowright, Stewart, Valentine, & Witthaus, 2007; Valenzuela et al., 2014). Given this, we believe that it is even more notable that relationships between certain predictor variables and SDM were significant. However, it does also indicate that there is a need to develop strong, reliable, and sensitive instruments to measure SDM in this population. The CAHPS measure used in the present study was brief and ideally suited to surveying a large sample of caregivers as part of a multi-site study. However, the measure was originally developed for use in primary care settings. While time-intensive measures for coding provider-patient interactions exist and some have been adapted for use with caregivers (Brinkman et al., 2011; Elwyn et al., 2003), there is still a need for brief, reliable measures for caregiver- and adolescent-report of SDM in chronic care settings. SDM measures for chronic care settings would benefit from including specific items to clarify differences that occur in decision-making with various providers on a multidisciplinary team (e.g., nurses, physicians, educators, dieticians, etc.) and to clarify differences in decision-making at specific points of contact (e.g., during appointments, through email and phone contacts between appointments, during inpatient admissions, etc.) This would likely result in more variability in caregiver- and patient-report and could potentially improve the sensitivity of SDM measurement. One example of a promising effort in this area is the new Decision-Making Involvement Scale (DMIS) developed for children and adolescents with cystic fibrosis, diabetes, and asthma to measure child decision-making involvement using child- and caregiver-report on twenty survey items (Miller & Harris, 2011). Ideally, measures like these will be studied in ways that help us to make clinically meaningful interpretations (e.g., what level, if any, of improvement is associated with a 1-unit change in SDM on a particular measure). In addition, these measures may be useful in the training of diabetes specialists, and healthcare providers in general, given evidence that providers do not correctly predict patient’s rating about provider-patient interactions and their quality (Bieber, Müller, Nicolai, Hartmann, & Eich, 2010). Despite the current study’s limitations, it remains one of the first to examine SDM among caregivers of youth with T1D and provides much needed data that can be used to build upon for future studies.

## Conclusions

While many caregivers report high SDM in the care of their youth with T1D, families with lower levels of caregiver-reported SDM may be experiencing poor self-care. Further studies, including both longitudinal and controlled interventions designs, are needed to better understand the mechanisms through which SDM and glycemic control are related and to examine longer-term outcomes associated with SDM. The potential benefits of interventions

such as decision aids and support systems should be examined, as well as provider and patient interventions to increase family participation in care and potentially improve diabetes health outcomes (Applegate et al., 2003; Mullan et al., 2009). More research is needed to understand who would benefit most from these interventions and how to best tailor them for youth with T1D.

## Acknowledgments

The SEARCH for Diabetes in Youth Study is indebted to the many youth and their families, and their health care providers, whose participation made this study possible.

Grant Support: SEARCH for Diabetes in Youth is funded by the Centers for Disease Control and Prevention (PA numbers 00097, DP-05-069, and DP-10-001) and supported by the National Institute of Diabetes and Digestive and Kidney Diseases.

Site Contract Numbers: Kaiser Permanente Southern California (U48/CCU919219, U01 DP000246, and U18DP002714), University of Colorado Denver (U48/CCU819241-3, U01 DP000247, and U18DP000247-06A1), Kuakini Medical Center (U58CCU919256 and U01 DP000245), Children's Hospital Medical Center (Cincinnati) (U48/CCU519239, U01 DP000248, and U18DP002709), University of North Carolina at Chapel Hill (U48/CCU419249, U01 DP000254, and U18DP002708), University of Washington School of Medicine (U58/CCU019235-4, U01 DP000244, and U18DP002710-01), Wake Forest University School of Medicine (U48/CCU919219, U01 DP000250, and 200-2010-35171).

The authors wish to acknowledge the involvement of General Clinical Research Centers (GCRC) at the South Carolina Clinical & Translational Research (SCTR) Institute, at the Medical University of South Carolina (NIH/NCRG Grant number UL1RR029882); Seattle Children's Hospital (NIH CTSA Grant UL1 TR00423 of the University of Washington); University of Colorado Pediatric Clinical and Translational Research Center (CTRC) (Grant Number UL1 TR000154) and the Barbara Davis Center at the University of Colorado at Denver (DERC NIH P30 DK57516); and the National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant 8 UL1 TR000077; and the Children with Medical Handicaps program managed by the Ohio Department of Health.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention and the National Institute of Diabetes and Digestive and Kidney Diseases.

## References

- Agency for Healthcare Research and Quality. CAHPS(tm) 2.0 Questionnaires. 1998. Retrieved from <https://cahps.ahrq.gov/>
- Applegate H, Webb PM, Elkin TD, Neul SKT, Drabman RS, Moll GW, Megason G. Improving Parent Participation at Pediatric Diabetes and Sickle Cell Appointments Using a Brief Intervention. *Children's Health Care*. 2003; 32(2):125–136.10.1207/S15326888CHC3202\_4
- Beresford BA, Sloper P. Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *Journal of Adolescent Health*. 2003; 33(3):172–179.10.1016/S1054-139X(03)00047-8 [PubMed: 12944007]
- Beverly EA, Ganda OP, Ritholz MD, Lee Y, Brooks KM, Lewis-Schroeder NF, Weinger K. Look Who's (Not) Talking Diabetic patients' willingness to discuss self-care with physicians. *Diabetes Care*. 2012; 35(7):1466–1472.10.2337/dc11-2422 [PubMed: 22619085]
- Bieber C, Müller KG, Nicolai J, Hartmann M, Eich W. How does your doctor talk with you? Preliminary validation of a brief patient self-report questionnaire on the quality of physician-patient interaction. *Journal of Clinical Psychology in Medical Settings*. 2010; 17(2):125–136.10.1007/s10880-010-9189-0 [PubMed: 20217195]
- Bradley C, Plowright R, Stewart J, Valentine J, Witthaus E. The Diabetes Treatment Satisfaction Questionnaire change version (DTSQc) evaluated in insulin glargine trials shows greater responsiveness to improvements than the original DTSQ. *Health Qual Life Outcomes*. 2007; 5:57. [PubMed: 17927832]

- Brinkman WB, Hartl J, Rawe LM, Sucharew H, Britto MT, Epstein JN. Physicians' Shared Decision-Making Behaviors in Attention-Deficit/Hyperactivity Disorder Care. *Archives of Pediatrics and Adolescent Medicine*. 2011; 165(11):1013–1019.10.1001/archpediatrics.2011.154 [PubMed: 22065181]
- Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science & Medicine*. 1999; 49(5):651–661. [PubMed: 10452420]
- Dabelea D, Bell RA, D'Agostino RB Jr, Imperatore G, Johansen JM, Linder B, Waitzfelder B. Incidence of diabetes in youth in the United States. *JAMA: The Journal of the American Medical Association*. 2007; 297(24):2716–2724.10.1001/jama.297.24.2716 [PubMed: 17595272]
- Elwyn G, Edwards A, Wensing M, Hood K, Atwell C, Grol R. Shared decision making: developing the OPTION scale for measuring patient involvement. *Quality and Safety in Health Care*. 2003; 12(2):93–99.10.1136/qhc.12.2.93 [PubMed: 12679504]
- Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared Decision-Making in Pediatrics: A National Perspective. *Pediatrics*. 2010; 126(2):306–314.10.1542/peds.2010-0526 [PubMed: 20624804]
- Fiks AG, Mayne S, Localio AR, Alessandrini EA, Guevara JP. Shared decision-making and health care expenditures among children with special health care needs. *Pediatrics*. 2012; 129(1):99–107.10.1542/peds.2011-1352 [PubMed: 22184653]
- Gagnon EM, Recklitis CJ. Parents' decision-making preferences in pediatric oncology: the relationship to health care involvement and complementary therapy use. *Psycho-Oncology*. 2003; 12(5):442–452.10.1002/pon.655 [PubMed: 12833557]
- Golin C, DiMatteo MR, Duan N, Leake B, Gelberg L. Impoverished Diabetic Patients Whose Doctors Facilitate Their Participation in Medical Decision Making Are More Satisfied with Their Care. *Journal of General Internal Medicine*. 2002; 17(11):866–875.10.1046/j.1525-1497.2002.20120.x
- Harris MA, Wysocki T, Sadler M, Wilkinson K, Harvey LM, Buckloh LM, White NH. Validation of a structured interview for the assessment of diabetes self-management. *Diabetes Care*. 2000; 23(9): 1301–1304. [PubMed: 10977022]
- Heisler M, Cole I, Weir D, Kerr EA, Hayward RA. Does physician communication influence older patients' diabetes self-management and glycemic control? Results from the Health and Retirement Study (HRS). *The Journals of Gerontology Series A, Biological Sciences and Medical Sciences*. 2007; 62(12):1435–1442.
- Helgeson VS, Reynolds KA, Siminerio L, Escobar O, Becker D. Parent and adolescent distribution of responsibility for diabetes self-care: links to health outcomes. *Journal of Pediatric Psychology*. 2008; 33(5):497–508.10.1093/jpepsy/jsm081 [PubMed: 17848390]
- Ho M, Marger M, Beart J, Yip I, Shekelle P. Is the Quality of Diabetes Care Better in a Diabetes Clinic or in a General Medicine Clinic? *Diabetes Care*. 1997; 20(4):472–475.10.2337/diacare.20.4.472 [PubMed: 9096962]
- Ingram DD, Parker JD, Schenker N, Weed JA, Hamilton B, Arias E, Madans JH. United States Census 2000 Population with Bridged Race Categories. *Vital Health Stat II*. 2003; 135:1–55.
- Institute of Medicine (IOM). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, D.C: National Academy Press; 2001. Retrieved from <http://www.nap.edu/openbook.php?isbn=0309072808>
- Institute of Medicine (IOM), Committee on Comparative Effectiveness Research Prioritization. *Initial National Priorities for Comparative Effectiveness Research*. Washington, D.C: National Academy Press; 2009.
- Klostermann BK, Slap GB, Nebrig DM, Tivorsak TL, Britto MT. Earning trust and losing it: adolescents' views on trusting physicians. *The Journal of Family Practice*. 2005; 54(8):679–687. [PubMed: 16061053]
- Levetown M. Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics*. 2008; 121(5):e1441–e1460.10.1542/peds.2008-0565 [PubMed: 18450887]
- Maddigan SL, Majumdar SR, Johnson JA. Understanding the complex associations between patient provider relationships, self-care behaviours, and health-related quality of life in type 2 diabetes: A

structural equation modeling approach. *Quality of Life Research*. 2005; 14(6):1489–1500.10.1007/s11136-005-0586-z [PubMed: 16110929]

Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*. 2006; 60(3):301–312.10.1016/j.pec.2005.06.010 [PubMed: 16051459]

Merenstein D, Diener-West M, Krist A, Pinneger M, Cooper LA. An Assessment of the Shared-Decision Model in Parents of Children With Acute Otitis Media. *Pediatrics*. 2005; 116(6):1267–1275.10.1542/peds.2005-0486 [PubMed: 16322146]

Miller VA, Harris D. Measuring Children's Decision-Making Involvement Regarding Chronic Illness Management. *Journal of Pediatric Psychology*. 2011;10.1093/jpepsy/jsr097

Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. 2006; 9(1):25–36.10.1111/j.1369-7625.2006.00359.x [PubMed: 16436159]

Mullan RJ, Montori VM, Shah ND, Christianson TJH, Bryant SC, Guyatt GH, Smith SA. The diabetes mellitus medication choice decision aid: a randomized trial. *Archives of Internal Medicine*. 2009; 169(17):1560–1568.10.1001/archinternmed.2009.293 [PubMed: 19786674]

Peek M, Wilson S, Gorawara-Bhat R, Odoms-Young A, Quinn M, Chin M. Barriers and Facilitators to Shared Decision-making Among African-Americans with Diabetes. *Journal of General Internal Medicine*. 2009; 24(10):1135–1139.10.1007/s11606-009-1047-0 [PubMed: 19578818]

Peerzada JM, Schollin J, Håkansson S. Delivery room decision-making for extremely preterm infants in Sweden. *Pediatrics*. 2006; 117(6):1988–1995.10.1542/peds.2005-1885 [PubMed: 16740840]

Petitti DB, Klingensmith GJ, Bell RA, Andrews JS, Dabelea D, Imperatore G, Mayer-Davis E. Glycemic Control in Youth with Diabetes: The SEARCH for Diabetes in Youth Study. *The Journal of Pediatrics*. 2009; 155(5):668–672.e3.10.1016/j.jpeds.2009.05.025 [PubMed: 19643434]

Reiss JG, Gibson RW, Walker LR. Health Care Transition: Youth, Family, and Provider Perspectives. *Pediatrics*. 2005; 115(1):112–120.10.1542/peds.2004-1321 [PubMed: 15629990]

SEARCH for Diabetes in Youth Study Group. SEARCH for Diabetes in Youth: a multicenter study of the prevalence, incidence and classification of diabetes mellitus in youth. *Controlled Clinical Trials*. 2004; 25(5):458–471.10.1016/j.cct.2004.08.002 [PubMed: 15465616]

SEARCH for Diabetes in Youth Study Group. The Burden of Diabetes Mellitus Among US Youth: Prevalence Estimates From the SEARCH for Diabetes in Youth Study. *Pediatrics*. 2006; 118(4):1510–1518.10.1542/peds.2006-0690 [PubMed: 17015542]

Silverstein J, Klingensmith G, Copeland K, Plotnick L, Kaufman F, Laffel L, Clark N. Care of Children and Adolescents With Type 1 Diabetes A statement of the American Diabetes Association. *Diabetes Care*. 2005; 28(1):186–212.10.2337/diacare.28.1.186 [PubMed: 15616254]

Skinner EA, Diette GB, Algatt-Bergstrom PJ, Nguyen TTH, Clark RD, Markson LE, Wu AW. The Asthma Therapy Assessment Questionnaire (ATAQ) for Children and Adolescents. *Disease Management*. 2004; 7(4):305–313.10.1089/dis.2004.7.305 [PubMed: 15671787]

Sturm LA, Mays RM, Zimet GD. Parental beliefs and decision making about child and adolescent immunization: from polio to sexually transmitted infections. *Journal of Developmental and Behavioral Pediatrics: JDBP*. 2005; 26(6):441–452. [PubMed: 16344662]

Tates K, Meeuwesen L. Doctor-parent-child communication. A (re)view of the literature. *Social Science & Medicine* (1982). 2001; 52(6):839–851. [PubMed: 11234859]

Valenzuela JM, Seid M, Waitzfelder B, Anderson AM, Beavers DP, Dabelea DM. SEARCH for Diabetes in Youth Study Group. Prevalence of and Disparities in Barriers to Care Experienced by Youth with Type 1 Diabetes. *The Journal of Pediatrics*. 2014;10.1016/j.jpeds.2014.01.035

Van Dam HA, van der Horst F, van den Borne B, Ryckman R, Crebolder H. Provider-patient interaction in diabetes care: effects on patient self-care and outcomes. A systematic review. *Patient Education and Counseling*. 2003; 51(1):17–28. [PubMed: 12915276]

Williams GC, Freedman ZR, Deci EL. Supporting Autonomy to Motivate Patients With Diabetes for Glucose Control. *Diabetes Care*. 1998; 21(10):1644–1651.10.2337/diacare.21.10.1644 [PubMed: 9773724]

- Wilson SR, Strub P, Buist AS, Knowles SB, Lavori PW, Lapidus J, Vollmer WM. Shared Treatment Decision Making Improves Adherence and Outcomes in Poorly Controlled Asthma. *American Journal of Respiratory and Critical Care Medicine*. 2010; 181(6):566–577.10.1164/rccm.200906-0907OC [PubMed: 20019345]
- Wissow LS, Roter D, Bauman LJ, Crain E, Kerckmar C, Weiss K, Mohr B. Patient-provider communication during the emergency department care of children with asthma. The National Cooperative Inner-City Asthma Study, National Institute of Allergy and Infectious Diseases, NIH, Bethesda, MD. *Medical Care*. 1998; 36(10):1439–1450. [PubMed: 9794338]
- Worchel FF, Prevatt BC, Miner J, Allen M, Wagner L, Nation P. Pediatrician's Communication Style: Relationship to Parent's Perceptions and Behaviors. *Journal of Pediatric Psychology*. 1995; 20(5): 633–644.10.1093/jpepsy/20.5.633 [PubMed: 7500235]
- Zgibor JC, Songer TJ, Kelsey SF, Drash AL, Orchard TJ. Influence of Health Care Providers on the Development of Diabetes Complications Long-term follow-up from the Pittsburgh Epidemiology of Diabetes Complications Study. *Diabetes Care*. 2002; 25(9):1584–1590.10.2337/diacare.25.9.1584 [PubMed: 12196431]

**Table 1**

Demographics and Clinical Characteristics of 439 Youth with Type 1 Diabetes at their 24-Month Follow-Up Study Visit: SEARCH for Diabetes in Youth, 2002–2005.

<b>Demographic Characteristics</b>	<b><i>M</i> ± <i>SD</i> <i>N</i> (%)</b>	<b>Clinical Characteristics</b>	<b><i>M</i> ± <i>SD</i> <i>N</i> (%)</b>
Age at visit (years)	11.7 ± 3.7	Diabetes duration (years)	3.2 ± 0.7
Race/ethnicity		Age at diagnosis (years)	8.1 ± 3.7
White, non-Hispanic	341 (78.6)	Insulin Regimen	
Black, non-Hispanic	42 (9.7)	Conventional	45 (10.4)
Hispanic	38 (8.8)	Basal/Bolus	194 (44.9)
Asian/Pacific Islander	13 (3.0)	Insulin Pump	193 (44.7)
Highest Caregiver Education		Diabetes Care Provider	
Less than HS Graduate	8 (1.8)	Ped. Endocrinologist	291 (66.4)
High School Graduate	64 (14.7)	Nurse Practitioner	119 (27.2)
Some College	155 (35.5)	Other	28 (6.4)
College Graduate or More	210 (48.1)	HbA1c% ( <i>M</i> ± <i>SD</i> )	8.5 ± 1.5
		Self-Care Composite Score	47.1 ± 7.8



**Table 2**

Distribution of Responses to Shared Decision-Making Items among Caregivers of 334 Youth with Type 1 Diabetes Reporting Any Health Care Decisions in the Past 12 Months: SEARCH for Diabetes in Youth Study, 2002–2005.

	Offered Choices <i>N</i> (%)	Discussed Choices <i>N</i> (%)	Asked Your Preference <i>N</i> (%)	Involved You in Decision <i>N</i> (%)
Never	18 (5.4)	12 (3.6)	22 (6.6)	9 (2.7)
Sometimes	38 (11.4)	27 (8.1)	43 (12.9)	17 (5.1)
Usually	102 (30.5)	91 (27.3)	98 (29.3)	82 (24.6)
Always	176 (52.7)	204 (61.1)	171 (51.2)	226 (67.7)
Item Average ( <i>M</i> ± <i>SD</i> )	3.31 ± 0.88	3.46 ± 0.79	3.25 ± 0.92	3.57 ± 0.71

Note: Each column with data reflects one item from the SDM Composite Score.

The exact wording of each question is provided in the text.

**Table 3**

Multiple Linear Regression Predicting Caregivers SDM Score for 282 Youth\* with Type 1 Diabetes, SEARCH for Diabetes in Youth Study, 2002–2005

Variable	<i>B</i>	<i>SE B</i>	<i>P</i>
Age (1-yr increase)	0.04	0.01	0.01
Race/Ethnicity			0.44
White vs. Black	0.04	0.15	
White vs. Hispanic	−0.25	0.16	
White vs. Asian/PI	−0.00	0.23	
Highest Parental Education			0.15
HS or less vs. Some College	−0.14	0.13	
HS or less vs. College Degree	0.03	0.13	
Diabetes Provider (Peds Endo vs. Other)	0.19	0.09	0.04
Insulin Regimen (Conventional vs. Intensive)	−0.01	0.16	0.97
Self-Care Composite (1-unit increase)	0.01	0.01	0.11
HbA1c% (1% absolute increase)	−0.08	0.03	0.01

\* 46 participants were excluded from the analyses due to missing A1c results, and another 6 had missing data on at least one other variable of interest

**Table 4**

Multiple Logistic Regression Model Predicting Caregiver-Report of Any Healthcare Decision(s) in the Past 12 Months among 375 Youth\* with Type 1 Diabetes: SEARCH for Diabetes in Youth Study, 2002–2005.

Variable	Odds Ratio	95% CI	P
Age (1-yr increase)	0.97	0.90, 1.05	0.42
Race/Ethnicity			0.18
White vs. Black	0.55	0.20, 1.49	
White vs. Hispanic	1.38	0.61, 3.10	
White vs. Asian/PI	0.17	0.02, 1.53	
Highest Parental Education			0.14
Some College vs. HS or less	2.01	1.00, 4.04	
College Degree vs. HS or less	1.69	0.86, 3.31	
Provider (Peds Endo vs. Other)	1.74	1.05, 2.90	0.03
Regimen (Intensive vs. Conventional)	1.65	0.76, 3.60	0.21
Self-Care Composite (1-unit increase)	1.04	1.01, 1.08	0.02
HbA1c Percent (1 % absolute increase)	1.09	0.91, 1.31	0.34

\* 52 participants were excluded due to missing A1c results, and another 12 had missing data on at least one other variable of interest